



# NETWORK NEWS

News from the Utah Birth Defect Network

July 2007 <http://health.utah.gov/birthdefect> Volume 4, Issue 2

## UBDN Gets Funded!

As the 2007 Legislative Session neared completion, in a filled to capacity committee room on Capitol Hill, the Executive Appropriations Committee released its 2008 budget recommendations. A few minutes later, Marcia Feldkamp received a call from Steve McDonald of the March of Dimes giving her bad news and the good news. The bad news was the portable freezer outside the Senate Chambers was out of Fat Boy ice cream sandwiches. The good news was the Utah Birth Defect Network was funded!

Less than a month later Governor Huntsman signed the budget bill which included ongoing state funding for the Utah Birth Defect Network beginning in July 2007.

The Utah Chapter of the March of Dimes had been lobbying this issue relentlessly for two years. The chapter coordinated lobbying efforts by utilizing a strong advocacy network, setting up meetings with the Governor's office and key legislators, utilizing key contacts, coordinating key meetings with both health department officials and key appropriations committee members, testifying at several hearings, and holding a legislative event.

During the many interactions with elected officials one message resonated time after time - legislators listen to their constituents. Every phone call, email, letter or personal visit you made produced fruit in educating and convincing our legislature about

the need for and value of the UBDN.

The efforts of so many over the past two years are captured in a quote by Helen Keller. "The world is moved along, not only by the mighty shoves of its heroes, but also by the aggregate of the tiny pushes of each honest worker."

The March of Dimes is so appreciative of the "mighty shoves" and the many "tiny pushes" of those individuals who advocated for the Utah Birth Defect Network.

**Steve McDonald, March of Dimes**



## What can we do to help?

As parents of children with a birth defect, we may sometimes feel that our efforts won't make a difference. I can tell you that they do. The Utah Birth Defect Network is now funded because of people who want to make a difference. We are all faced with similar challenges that are a result of birth defects. I invite you to ask yourself, "What kind of help or support do I need, and what do I have to offer?"

Many of us feel like others need the help more than we do, and if so, we may then be in a position to provide that help and support.

The Utah Birth Defect Network is here to help, but we need to let them know what they can do to best help us. Some suggestions include workshops and networking groups to address and discuss primary prevention, prevention of complications, health insurance, access to care, and other issues

that we all face on a daily basis.

Do you have any suggestions that the Utah Birth Defect Network can implement to better support you as a parent or individual affected by a birth defect? Please contact Amy Nance at 866-818-7096 or at [anance@utah.gov](mailto:anance@utah.gov). Let your voice be heard, and make a difference.

**Ryan Bott, Parent**

### Inside this issue:

Family Conference a Great Success	2
21st Annual SOFT Conference	2
People with Chromosomal Conditions: a growing community	3

### Utah Birth Defect Network

P.O. Box 144699

Salt Lake City, Utah

84114-4699

Phone Number: 801-257-0566

Fax Number: 801-257-0572

Toll-Free: 866-818-7096



Promote Prevent Protect  
**Utah  
Department  
of Health**

# Family Conference a Great Success

The Utah Birth Defect Network and the March of Dimes Utah Chapter recently hosted an annual Family Conference for all individuals in the state who have been impacted by birth defects.

The event was attended by over 80 people, and the keynote speaker was Michael Ballam, Ph.D. Dr Ballam is a native of Logan, UT and has a 14 year-old son with spina bifida.

After an inspirational musical program by Dr. Ballam, conference attendees split into break-out sessions. Each break-out session addressed different concerns facing those affected by birth defects.

One session was conducted by Lorenzo Botto, M.D. He led a discussion on various quality of life issues faced by those with birth defects. These issues are multi-faceted and include helping parents and children have the most fulfilling life possible despite challenges related to birth defects.

The second break-out session was conducted by UBDN Director Marcia Feldkamp. This session focused on recent exciting developments at the Utah Birth Defect Network, including current epidemiological studies and research findings. After the break-out sessions, attendees were treated to a light lunch and given an opportunity for connecting with other families in at-

tendance. Following lunch, attendees were able to participate in a question and answer forum. The expert panel consisted of four parents of children with birth defects. Many issues including teasing, siblings, and pain management were addressed by the panel.

Special thanks to all the families and friends who attended and actively participated in this wonderful community resource. We are looking forward to next year's annual Utah Birth Defect Network conference.

**Kristin Fowles, Parent**

If you would like to be involved in planning next years family meeting, contact Amy at 866-818-7096 or [aenance@utah.gov](mailto:aenance@utah.gov).



## 21st Annual SOFT Conference

The Support Organization for Trisomy 18, 13, and Related Disorders (SOFT) will hold their annual conference in Salt Lake City this year July 5-7th.

SOFT is a parent advocacy group for families of persons with these medically serious chromosome conditions. Individuals with trisomy 18 and 13 have numerous medical challenges, including structural birth defects (such as heart malformations), increased infant mortality and significant developmental disabilities.

Established in Utah by two mothers of children with trisomy 18 in 1979, SOFT publishes a quarterly newsletter for families and professionals, hosts the annual conference and provides support for thousands of families throughout the world.

This year's meeting will occur at the University Guest House on the campus of the University of Utah and features lectures, workshops, seminars and social gatherings for the attendees; the 2007 conference, the 21<sup>st</sup>, includes a unique event- the annual balloon release - honoring the

infants, children and adults with these conditions who have died.

In addition to the conference, Primary Children's Medical Center will sponsor a multidisciplinary clinic on Friday, July 6<sup>th</sup>. Various health professionals have volunteered their time to see interested families for the half day clinic.

Information on the conference is available on the SOFT web page at [www.trisomy.org](http://www.trisomy.org).

**John Carey, M.D., M.P.H., F.A.A.P.**

Would you like to help the Utah Birth Defect Network grow?

We are working on prevention activities and educating the public about birth defects in Utah.

Please call us at (866) 818-7096 or (801) 257-0566

# People with Chromosomal Conditions: a Growing Community

It may come as a surprise to learn how common chromosomal conditions are as a group (Table). Many of us know people with Down syndrome, but collectively, chromosomal anomalies occur in about 1 in 315 births in Utah (Table). At the Utah Birth Defect Network (UBDN), a public health program of the Department of Health, we recognize the importance of chromosomal anomalies, common and less common, and the special needs of people with these conditions and their families.

Because Utah has over 50,000 births per year (and rising), the community of people with these conditions and their families is quite

large. What can be done for diagnosis, management, and support? An evaluation by a medical genetics team can be very helpful, to support the family and the primary care provider with assessing medical needs, and, where possible, anticipate or prevent complications.

This assessment can also help evaluate recurrence risk, whether it is associated with maternal age, or with a chromosomal rearrangement in a parent.

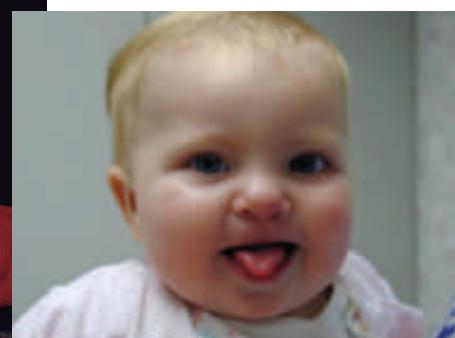
Ongoing monitoring by the Utah Birth Defect Network is crucially important to ensure that needs are known and understood, so that services can be adequately planned. For individual families, learning about resources is impor-

tant. Some of these can be found on the UBDN website: (<http://health.utah.gov/birthdefect>), but if you know of others, please let us know, so we can share them. (Remember the annual meeting for families, which the UBDN and the March of Dimes organizes every February.) Information for next year's meeting will be available on the UBDN website at year's end and don't forget the SOFT meeting this July 5-7 in Salt Lake City.

Lorenzo Botto, MD

**Table. Select chromosomal anomalies among livebirths and stillbirths in Utah. Source: Utah Birth Defect Network, based on births from 1999 through 2002, with ascertainment through 2006**

Condition	Average number born yearly in UT	Average birth frequency
<b>Common trisomies</b>		
Down syndrome (Trisomy 21)	85	1 in 650
Trisomy 18	19	1 in 2,890
Trisomy 13	8	1 in 6,570
<b>Deletions</b>		
deletion 22q11	10	1 in 5,780
deletion 4p (Wolff-Hirschhorn)	1	1 in 47,660
deletion 5p (Cri-du-chat)	1	1 in 95,310
Prader Willi syndrome (deletion only)	3	1 in 21,180
Other deletions	16	1 in 3,530
<b>Anomalies of sex chromosomes</b>		
45, X (Turner syndrome)	15	1 in 3,600
Other chromosomal anomalies	18	1 in 3,070
Any of the above conditions	175	1 in 315



Utah Birth Defect Network  
PO Box 144699-4699  
Salt Lake City, Utah 84114-4699

STAMP



Check out our Web site!  
[www.health.utah.gov/birthdefect](http://www.health.utah.gov/birthdefect)

Place Label Here

ALL DRINKS WITH ALCOHOL  
CAN HURT AN UNBORN BABY

A photograph of a pregnant woman in a green tank top and light-colored pants, sitting on a bed and gently holding her pregnant belly. To the right of the image is a vertical bar with horizontal stripes in purple, yellow, and green.

IF YOU DRINK  
DON'T GET PREGNANT

IF YOU'RE PREGNANT  
DON'T DRINK

THIS MESSAGE IS BROUGHT TO YOU BY  
UTAH DEPARTMENT OF HEALTH, UTAH FETAL  
ALCOHOL COALITION, MARCH OF DIMES AND THE  
UTAH DEPARTMENT OF ALCOHOLIC BEVERAGE CONTROL

The Utah Birth Defect Network and the Pregnancy Risk Line, are working to educate women of child-bearing age on the importance of abstaining from alcohol before conception, during pregnancy and while breast feeding.

As you are aware, binge drinking and heavy alcohol use during pregnancy can cause problems for children resulting in Fetal Alcohol Spectrum Disorders (FASD). Some of the problems include:

- Facial changes
- Low birth weight
- Brain damage
- Heart defects
- Fetal death
- Learning and behavior problems

The Alcohol Postcard was created by several Utah agencies to be distributed by providers to their patients.

If you would like to order these cards for your practice which are free of charge.

Please contact Amy Nance at 866-818-7096 or [aenance@utah.gov](mailto:aenance@utah.gov) to place an order.